**Informative Research Product Organizer**

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| **Research Topic:** Pediatric Cancer |

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| **Focusing Statement:** Pediatric Cancer and its effects on the family and surrounding community |

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| **Essential Background Information for Introduction:**   * Cancer (defined by the National Cancer Institute) - A term for diseases in which abnormal cells divide without control and can invade nearby tissues. Cancer cells can also spread to other parts of the body through the blood and lymph systems.   + Carcinoma is a cancer that begins in the skin or in tissues that line or cover internal organs.   + Sarcoma is a cancer that begins in bone, cartilage, fat, muscle, blood vessels, or other connective or supportive tissue.   + Leukemia is a cancer that starts in blood-forming tissue such as the bone marrow, and causes large numbers of abnormal blood cells to be produced and enter the blood.   + Lymphoma and multiple myeloma are cancers that begin in the cells of the immune system.   + Central nervous system cancers are cancers that begin in the tissues of the brain and spinal cord.   + Also called malignancy. * Leukemia (Cancer that starts in blood-forming tissue such as the bone marrow and causes large numbers of blood cells to be produced and enter the bloodstream) and cancers of the central nervous system (The brain and spinal cord. Also called CNS) and the brain are the most common types of cancer. |

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| **Potential Hook/Grabber (**Story, anecdote, quote about your issue**):**  Alex Hanson grew up in Columbia Falls, Montana, the oldest of three kids, living a normal life. He went to school, played sports and hung out with his family. Until at age 12, he was diagnosed with acute myeloid leukemia. That’s when everything changed…  (Continue to weave the story of the Hanson family throughout the organizer/project) |

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| **Topic 1:** The Basics | |
| **Explanation**   * 36 children in the United States are diagnosed with multiple kinds of cancer everyday * Approximately 12,500 children a year are diagnosed * 1 in every 330 Americans have cancer by age 20 * 1 in every 4 elementary students have cancer * 2,300 children and teenagers die a year | **Evidence/Quotes:**   * Alex’s Lemonade Stand - http://www.alexslemonade.org/resources/facts * Pediatric Cancer Foundation - http://www.pcfusa.org/facts\_faces.htm * THON -http://www.thon.org/whatisthon/cancer\_facts |
| **Explanation**   * central nervous system tumors – unfavorable diagnosis due to difficulty of surgery * increase of invasive cancer diagnosis in past 20 years (from 11.4 cases per 100,000 children in 1975 to 15.2 per 100,000 children in 1998) * number one disease killer of children * longer treatment periods- ex. Young leukemia patients undergo treatment for 2-3 yrs, most adult treatment- a few months | **Evidence/Quotes:**   * Morgan Adams Foundation--http://www.morganadamsfoundation.org/statistics.html * cancer.net * John Marris- associate professor of pediatrics at CHOP |

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| **Topic 2:** Severe effects on Family | |
| **Explanation** Isolation   * Diagnosis carries “weight” – the delicate state of health produces social isolation   Child = scared, nervous of diagnosis   * Mother- changes to emphasize day-to-day living, more direct care/concern   Example: Kathy Hanson, quits job and moves to Seattle to be quit son, focus on direct care | **Evidence/Quotes:**   * Annotated Bib #4 – Study conducted by Arturo Alvarez Roldan of the University of Granada |
| **Explanation** Finances   * Problems- one parent quits to care for child, single parents usually continue working away from the hospitalized child * Insurance costs- families w/ cancer patient, greater risk of exceeding maximum insurance benefits * Federal health insurance program for disabled – limit benefits to families earning less than $34,100 a year   + Thus most families do not receive these benefits | **Evidence /Quotes:**   * Annotated Bib #9 - Claudia Morain of UC-Davis Cancer Center * Douglas Taylor – director of pediatric bone-marrow transplant program at UC-Davis Cancer Center * U.S. Department of Health & Human Services |

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| **Topic 3:** Treatment and Costs | |
| **Explanation** Hospital expenses   * ICU Pediatric - $49,000 a day * travel via ambulance - $675 per 5 miles * most families live far from children’s hospitals b/c of pediatric cancer rarity | **Evidence/Quotes:**   * Annotated Bib #9 - facts & figures according to Kathy Hanson * Julie Komanetsky – National Children’s Cancer Society |
| **Explanation** Prescription Drugs   * Certain leukemia drug causes patient fatigue   + Want to improve the quality of life/patient care * Extremely expensive! Some cancers are so rare, companies are reluctant to make the drugs - no profit margin * The Creating Hope Act of 2011 provides market incentives to pharmaceutical companies to develop drugs for pediatric rare diseases. * Leukemia drug $45,000 for three week cycle   Financial pressure on family to afford drugs/care. | **Evidence/Quotes:**   * Annotated Bib #1 – 2007 Study by St. Jude Children’s Research Hospital * Annotated Bib #9 - information from drug company Genzyme |
| **Explanation** Clinical Trials   * Clinical trials are one of the fastest and safest ways to find treatments that work against cancer. * Approximately 75 percent of children with cancer in the United States will be treated on a clinical trial   + contrast to the 1 to 5 percent of adults with cancer who are enrolled in clinical trials. * Benefits- play an active role in health care, access to new research treatments before they are widely available, obtain expert medical care at leading health care facilities during the trial, help others by contributing to medical research * Risks- unpleasant, serious or even life-threatening side effects to experimental treatment, may not be effective for the participant, requires more of time and (trips to the study site, more treatments, hospital stays or complex dosage requirements) * Conducted in phases   + Phase I – test drug w/ small group (20-80) to evaluate safety, determine dosage range and identify side effects   + Phase II – given to larger group (100-300) to see effectiveness and continue evaluating safety   + Phase III – distributed to large the groups of people (1,000-3,000) to confirm its effectiveness, monitor side effects, compare it to commonly used treatments, and collect information   + Phase IV - post marketing studies delineate additional information including the drug's risks, benefits, and optimal use. | **Evidence /Quotes:**   * Sloan-Kettering Cancer Center http://www.mskcc.org/mskcc/html/2873.cfm * Clinical trials – U.S. National Institutes of Health http://clinicaltrials.gov/ct2/info/understand#Q01 |

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| **Topic 4:** The Community |
| **Explanation** Fundraisers / Organizations   * Alex’s Lemonade Stand – “to raise money for and awareness of childhood cancer causes—especially research into new treatments and cures—and to encourage and empower others, especially children, to get involved and make a difference for children with cancer.” * St. Jude Children’s Research Hospital- “The mission of St. Jude Children’s Research Hospital is to advance cures, and means of prevention, for pediatric catastrophic diseases through research and treatment. Consistent with the vision of our founder Danny Thomas, no child is denied treatment based on race, religion or a family's ability to pay. | **Evidence/Quotes:**   * Alex’s Lemonade Stand website - <http://www.alexslemonade.org/about> * St. Jude Children’s Research Hospital - <http://www.stjude.org/mission> |
| **Explanation (example)**   * Small scale- donating $, time, energy * $50,000 work to house done by community   + People see “desperate” family who are struggling – ethical/moral calling to help * National Children’s Cancer Society- contributions to families (example: Hanson’s - travel costs)   + Lodging   + Meals   + Transportation   + Health Insurance   + Medical Expenses not covered by insurance   + Phone cards * Hospitals write off treatment as charity - Children’s Hospital and Regional Medical Center (Seattle Children’s Hospital)   + Maximum insurance benefits reached | **Evidence/Quotes:**   * Annotated Bib #9 - Kathy Hanson * National Children’s Cancer Society - http://www.thenccs.org/page.aspx?pid=652 |
| **Explanation – Support Groups**   * Numerous local groups across the country   + focus on fundraising, direct help to families   + Children’s Cancer Community – San Francisco Bay Area, CA   + Pediatric Cancer Foundation of the Leigh Valley     - PCFLV is a local nonprofit organization which supports children with cancer and their families, enabling them to LIVE their lives to the fullest.     - focus on quality of life and long-term survivorship programs, educational and therapeutic based workshops, resources and support services, including a support group run by a professional facilitator | **Evidence /Quotes:**   * Pediatric Cancer Foundation of the Leigh Valley – <http://www.cancersupportgroup.org/> * Cancer Support Community –http://www.thewellnesscommunity.org/General-Documents/pennsylvania.aspx |

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| **Topic 5:** The Future: Surviving Childhood Cancer   * Generally grim outlook | |
| **Explanation**   * Increased health risks – heart disease, second cancers, infertility, damaged joints, learning disorders and more. due to the harsh treatments of the 1970s and early 1980s * Increased suicide rate of survivors   + 13% of 226 were suicidal   + 40% were depressed * PTSD   + CC survivors are 4 times more likely to develop PTSD in comparison to control group.   + Studied 6,542 survivors to 368 healthy siblings   + Symptoms- increased arousal, phobias, being easily startled, being hyper vigilant, avoiding reminders of cancer and suffering from anxiety | **Evidence/Quotes:**   * Annotated Bib #5 – Reported in The New England Journal of Medicine * Annotated Bib #7 – Study published in Journal of Clinical Oncology, conducted by researchers at the Dana-Farber’s Perini Family Survivors’ Center * Annotated Bib #3 – Study published in the medical journal entitled Pediatrics. Study conducted by Dr. Margaret Stuber of the Jonsson Cancer Center |
| **Explanation**  For today’s kids – generally unknown but face social, psychological and health problems. | **Evidence/Quotes:**  Annotated Bib #8 – CCSS study |
| **Explanation**   * CC survivors are four times less likely to find employment, in comparison to healthy people * Starting a family- babies of CC survivors (male or female) do not have an increased risk of birth defects * Less likely to marry – 25% more likely to never marry in comparison to health siblings   + Stems from physical effects (short stature, poor physical function and cognitive problems), leading to low self-esteem | **Evidence /Quotes:**   * Annotated Bib #5 – 2007 study in Pediatric Blood & Cancer * Annotated Bib #10 – 2009 study in The Archives of Pediatrics and Adolescent Medicine, conducted by researchers at the Fred Hutchinson Cancer Research Center in Seattle * Annotated Bib #2 – Study published in Cancer Epidemiology, Biomarkers & Prevention (American Association for Cancer Research) conducted by Yale School of Medicine, |